

THERAPY FOR PERSONS WHO STUTTER: EASTERN EUROPE AND LATIN AMERICA

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SUMMARY

The Fluency Committee of the IALP carried out a survey in Eastern Europe and Latin America in order to assess the therapy status of fluency disorders and service opportunities. Information was collected on prevalence and incidence rates, involvement of government-affiliated agencies, prices, insurance, social support, financing, information, and education about stuttering and stuttering therapy, training of speech language pathologists (logopeds), specialization in stuttering therapy, and cooperation with other specialists. Information was collected for five age groups: Infants and preschool children, primary school children, secondary school children, adolescents, and adults. The reported therapy approaches seemed to be appropriate. We recommend focus on development of efficacy.

1. Introduction

Therapeutic approaches, policies, services, and social support for persons who stutter (PWS) or who have other types of fluency disorders are often regarded to be insufficient or limited in underdeveloped or threshold countries. The aim of this study was to explore therapy standards and service opportunities as well as the education of professionals in the part of Europe which recently entered a process of transition into integration or association with the European Union. A comparable survey was also carried out in some Latin American countries. All these countries are in the process of transformation. They have already developed some standards and have good opportunities to implement international standards with support from the international professional community. The project was initiated by the Fluency Committee of the International Association of Logopedics and Phoniatrics (IALP) in the year 2004. The responses from this questionnaire are intended to be used for the improvement of the conditions of persons with fluency disabilities, and the data could be the basis for improving therapy and service opportunities in these countries.

2. Method

A questionnaire developed by Yoko Wakaba at the Research Institute for the Education of Exceptional Children (RIIEC), Tokyo Gakugei University, and Koichi Mori at the Research Institute of National Rehabilitation Centre for Persons with Disabilities was modified for the present purpose. Eleven main topics, with several questions each, were included:

- A. Incidence and prevalence
- B. Social support systems
- C. Available therapy and financing
- D. Therapy approaches, goals, and efficacy
- E. Information for the public
- F. Early detection, screening programs, and primary prevention
- G. Education and training of speech and language pathologists
- H. Specialization in stuttering therapy
- I. Cooperation with other specialists
- J. The need for improving the services of PWS
- K. Problems with optimal provision of care for PWS

When applicable the questions were adapted for five age groups: Infants and preschool children, primary school children, secondary school children, adolescents, and adults. In addition, information available for parents and the general public was also requested. The questionnaire was a paper-and-pencil survey in order to ensure that respondents did not need access to the internet. The main survey language was English but the form was translated into Bulgarian and Spanish as well. In June 2005 the forms were sent to professionals in stuttering therapy in European countries which recently underwent political, social, and economic transformation, and to the addresses of professionals in Latin America. Addresses were obtained from the International Fluency Association (IFA), the IALP and personal contacts. We encouraged the addressees to distribute the forms among fellow professionals in fluency disorders or to provide the authors with additional addresses. Originally, the forms were sent out to 60 persons. At the beginning of 2006 a reminder was sent to those who did not respond.

3. Results

Twenty-five responses were returned from the European countries Bulgaria (11), Croatia (2), Czech Republic (2), Estonia (4), Lithuania (1), Poland (2) Russia (2), and Slovak Republic (1). From Latin America eleven responses were returned from Argentina (1), Brazil (8), Mexico (1), and Uruguay (1).

A. Incidence and prevalence

An incidence rate was only reported for the Slovak Republic, given as 5% (Lechta, 2004). Prevalence rates for children were reported from Poland (5%), Russia (4%), and Lithuania (3 to 4%). The total prevalence in Eastern Europe, not distinguishing between children and adults, ranged from 0.98 to 2.70%. Argentina and Uruguay indicated prevalence between 1% and 2%. The only Eastern European official statistics came from The Czech Republic's National Statistical Office which reported a prevalence rate of 0.98%.

B. Social support systems

Generally the results of the survey from the participating countries demonstrated that there are no support arrangements available to help PWS with therapy, guidance or support in everyday life. The only available support is received from logopedic therapies. The Estonian Stuttering Association offers courses, special activities, and counselling, and for the Slovak Republic self help groups were mentioned.

From this survey it appears generally difficult to get support for coping with daily life. Stuttering associations provide some support while in Poland support is also offered by the logopedic association. Croatia, Lithuania, Russia, and Brazil do not offer any support. Several stuttering associations (in the Czech Republic also the logopedic associations) provide support related to the job market and the working situation. The Brazilian Stuttering Association has one lawyer in São Paulo who supports PWS who are discriminated at work, and some help may be provided through an e-mail to gagueira@yahoo.com.br

C. Available therapy and financing

Eastern Europe only

Children. All responding Eastern European countries provide children with stuttering therapy free of charge. Therapy is offered in kindergartens, schools, or within health services. Financing of professionals is provided by educational systems, health services, social insurance, or health insurance.

Adults. Adults in Croatia, the Czech Republic, Estonia, Lithuania and Poland receive financial assistance through the public health system or through health insurance. Bulgaria does not have any financial assistance for stuttering therapy.

In a number of countries only a limited number of therapy sessions are paid for (for instance in Lithuania 20 hours per year). The costs per session range from five to 20 Euro, and in private practice up to 27 Euro. A 25 days hospital course in Russia is 590 Euro.

Latin America only

In general, Latin America does not have financial assistance for stuttering therapy for children or adults. Only a few can afford private health insurance which sometimes covers stuttering therapies. There is a mixture of private settings, university clinics, free public hospitals, and charitable or mutual health institutions without stuttering specialization. In Uruguay therapy is free in public hospitals and also for health insured persons with a maximum of 10 months. Argentina has some free institutions, but in general parents have to pay 20 to 50 USD per session. Only a few private health insurances will reimburse costs for speech therapy there, sometimes only one session per month.

Eastern Europe and Latin America

Additionally, most of the responding countries have also private practices. It seems generally that, some health insurance companies will reimburse expenses partly or entirely, but often with some restrictions. Information about stuttering for parents and the public as well as locations which offer therapy for PWS differs from country to country. Information may also be provided by the logopedists in kindergartens, in schools, in hospitals, and in private practices. Also stuttering associations, logopedic associations, stuttering resource centers, university clinics, municipalities, and government agencies may offer face-to-face counseling. Telephone and e-mail communication, brochures, publications, media communication, and web-sites are also used.

D. Therapy approaches, goals, and efficacy

All countries have professional logopedists or speech therapists for stuttering therapy. In Croatia, Estonia, Poland, and Brazil, psychologists are also involved in stuttering therapy, and in Estonia neurologists may also provide therapy. Many different kinds of stuttering therapeutic approaches are reported, but fluency shaping therapy is the dominant approach. In fluency shaping therapies smooth speech and soft onset are the most common strategies. Other strategies reported are logorhythmic therapy, holistic phonographorhythmic therapy, and gradual increase in utterance length and complexity.

Under stuttering modification therapy, respondents included speaking openly about stuttering, behavior modification, operant conditioning, relaxation, speech anxiety reduction, self-control, desensitization, communicative rehabilitation, neurolinguistic approaches, and non-avoidance approach. Other therapeutic approaches mentioned are parent guidance, family therapy, physiotherapy, psychosocial approaches, or medication such as bronchodilatation with β_2 -sympatomimetics.

Therapy might be more or less extensive or intensive. Therapy goals are mostly fluent speech, better fluency, controlled stuttering, less stuttering, fluent stuttering, less speech anxiety and avoidance, and increased self confidence. Efficacy estimation is almost nonexistent. Predominantly case reports and self-evaluation are mentioned.

E. Information for the public

In all countries information about stuttering is provided for the public, by stuttering associations, stuttering centers, logopedic associations, and governmental agencies. Information might be given via TV, radio, brochures, special activities, open house days, the International Stuttering Awareness Day, and internet sites.

F. Early detection, screening programs, and primary prevention

Croatia, Czech Republic, Estonia, Lithuania, Poland, Russia, Slovak Republic, and Argentina have some system of early detection in kindergartens and schools, or by pediatric health checks. Bulgaria has no specific programs, and in Brazil only a few examples of such programs were mentioned by referring to Andrade (2004).

G. Education and training of logopeds

All countries offer a higher professional education for logopeds up to a diploma, bachelor's, master's, or doctoral degree. The clinical training hours vary between 80 and 1,000 hours. The clinical certification is authorized by the university, a governmental agency, or a logopedic association.

H. Specialization in stuttering therapy

Most countries provide a formal, institutionalized logopedic specialization for stuttering therapy organized by universities. In the Czech Republic, Lithuania, and Brazil there are non-formalized specialization. In Croatia and Estonia there is no specialization available. Clinical training hours in the specialization programs range from 40 to 500 hours.

I. Cooperation with other specialists

All countries report some sort of cooperation of logopeds with other disciplines. These specialists include psychologists, psychiatrists, neurologists, otolaryngologists, pediatricians, family doctors, special needs education teachers, and rehabilitation specialists. The cooperation with other specialists varies from country to country depending on the way stuttering therapy is embedded in the health and human service systems.

J. Needs for improving the services for PWS

The need to improve the services for PWS differs from country to country. There is a long list of requirements or suggestions which are mentioned. These concern stuttering therapy centers, the inclusion of stuttering therapy in the health services and health insurance, professional development activities for logopeds, specialization, certification in stuttering therapy, national organizations for specialists in fluency disorders, stuttering research, employment programs for PWS, counseling for PWS, local organizations for PWS, more public awareness and acceptance of stuttering, and motivation of PWS and their parents. In Latin America the implementation of decentralized services including preventive programs is strongly emphasized.

K. Problems with optimal provision of care for PWS

Optimal provision of care for PWS is limited by a number of specific problems in the various countries. Only the Czech Republic did not report any problem. The following is a summary of the problems mentioned in the responses.

- Bulgaria: Therapy is not provided by the health services and there is no financial support for adults who stutter. There are social problems for PWS. The respondent logopeds reported that too many of them are educated in the Russian tradition.
- Croatia: Too few specialists in stuttering. Long waiting lists. Lack of knowledge about stuttering among teachers and parents.
- Estonia: Sparse education about stuttering for logopeds and little public information.
- Lithuania: Little knowledge and motivation for stuttering therapy among PWS. Stuttering resource centers needed.

- Poland: Postgraduate education in stuttering therapy needs improvement. No social or financial support for PWS.
- Russia: Lack of legitimacy for those with disability, and no effective stuttering therapy approach.
- Slovakia: Health insurance does not cover long-term therapy.
- Argentina: Economic problems limit the services of the health system including services for PWS
- Brazil: Poverty and lack of health services, resources, legitimacy, and knowledge about stuttering.

4. Discussion and Conclusion

In this discussion section we would like to highlight and discuss the main results for the main topics presented above.

Rate of prevalence

The few indications of prevalence given by the responders are in the upper range of the international prevalence rates.

Social and financial support

In general there are no social supporting arrangements available to help PWS in therapy guidance, apart from therapy sessions, and in their everyday life concerning financial, educational, social and professional affairs. The main social support is provided by non-governmental organizations (NGO), such as stuttering associations and self-help groups. During therapy logopedes may also give some support. The options for children appear to be better than for adults, and therapy is provided through kindergartens and schools free of charge.

In most countries therapy is also available in private practices; however, PWS have to pay for themselves. Few PWS may have a private health insurance covering stuttering therapy. Thus, this status may reflect the former official socialistic ideology with its special attention on care for and education of children. The socialistic governments did not identify the needs of adult PWS, and in general public attention for persons with a disability was insufficient.

Stuttering therapy

All of the countries have professionally educated logopedes working with PWS and in some countries there are other professional groups who treat stuttering individuals; these may include psychologists and neurologists. All kinds of therapy approaches are reported, including Western European, and North American approaches. There are some reports of medication being used as well. The majority of stuttering therapy is provided through the health systems, except for the therapy provided through kindergartens and schools, and the professionals appreciate this organization of therapy. Therapy financing seems to be easier for children than for adults, and the establishment of a special "in-between group" of adolescents has no tradition as it has in other regions of the world. Bulgarian logopedes reported that they are fighting for the provision of stuttering therapy in the health services.

Providing information

Various providers of information for PWS, parents and the public are reported. Internet information and e-mails seem to have become an important source. Support in everyday and working life seems to be difficult to gain, and discrimination in the job market is reported to be a problem. The non-EU countries stress this problem more than the EU-countries, which may be related to the policy of EU, expressed in the EU Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation.

Cooperation

Cooperation with other specialists, is facilitated when stuttering therapy is provided in a multi-professional clinical setting, this differs between countries. However, therapy efficacy evaluation seems to be insufficient, contrasting with the development of evaluation assessments and best practice in Western Europe and North America. Early detection seems to some extent to be favoured in all countries.

Education

With one exception, education of logopedists is generally available up to university graduate level. The number of clinical training hours is extremely varied and appears comparatively high. All countries require a clinical certification. Postgraduate specialization in stuttering therapy ranges from non-existent to not formalized, formalized workshops, and formalized post-graduate education.

In general, the East European countries tend to move towards integration into an international fluency community. The sponsored memberships of the International Fluency Association and the guest lectures might have contributed to this development. The East European countries are stressing the same needs for improving the daily life of PWS as seen in Western countries. Especially Russian informants stress the lack of public attention for PWS and effective therapy. Latin America is focusing on poverty problems as the main hindrance for optimal care.

For stuttering therapy, Eastern Europe currently takes a positive and multifaceted development. A lot of different therapeutic approaches are reported to be used, but it should be recommended to the participating countries to improve the efficacy evaluation of their clinical practice. Russia might need more guidance in improving stuttering therapy standards. The overcoming of economic problems and more effective governance should improve the situation in Latin America.

We like to stress that the above findings are based on the questionnaires we received (50% of the mailed questionnaires). We much appreciate comments and additional information from professionals involved in stuttering in these countries.

Acknowledgement

We like to express our appreciation to Miglena Simonska, South-West University of Bulgaria, for translation of the questionnaire into Bulgarian and translation of the answers from Bulgaria, and Harald A. Euler, University of Kassel, for assistance in preparing the questionnaire and the manuscript. We also like to thank all the informants in Europe and Latin America.

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